

Name-based HIV Reporting in Virginia

- The First 10 Years -

Introduction. June 30, 1999, marked the completion of the first ten years of HIV name-based reporting in Virginia. The multitude of changes that occurred during this ten-year period, such as the impact of improved HIV treatment regimens, have had far-reaching implications on the HIV/AIDS epidemic, from both a programmatic and epidemiological perspective. Virginia's foresight regarding the benefits of instituting HIV name-based reporting is allowing the Division of HIV/STD to maintain a progressive approach to handling the epidemic.

The Division of HIV/STD began collecting name-based data for all HIV cases on July 1, 1989. At that time, HIV case surveillance activities were combined with AIDS and other STD case surveillance activities, making Virginia one of the first combined STD/HIV/AIDS programs in the nation.

Seventeen states preceded Virginia with some form of name-based HIV reporting, the first state having initiated reporting in October 1985 (Figure 1). As of February 1999, a total of 31 states have mandated confidential name-based reporting for adolescent and adult HIV cases. Two states require named reporting of pediatric HIV cases only.¹

By 2003, the Centers for Disease Control and Prevention (CDC) intends to institute a national strategy for HIV/AIDS surveillance, including both HIV and AIDS case reporting as the minimal standard. This has prompted states with no HIV reporting to

promulgate HIV reporting procedures to comply with possible new federal surveillance regulations.

Confidentiality. The issue of confidentiality has been the primary source of contention, among opponents to name-based testing, since the inception of HIV/AIDS reporting.

Figure 1. States with named HIV Reporting Ranked by Initiation Date⁸

1	Minnesota	Oct. 1985
2	Colorado	Nov. 1985
2	Wisconsin	Nov. 1985
4	<i>South Carolina</i>	Feb. 1986
5	<i>Idaho</i>	June 1986
6	Arizona	Jan. 1987
7	Missouri	Oct. 1987
8	<i>Alabama</i>	Jan. 1988
8	<i>North Dakota</i>	Jan. 1988
8	<i>South Dakota</i>	Jan. 1988
11	Oklahoma	June 1988
12	Indiana	July 1988
13	<i>Mississippi</i>	Aug. 1988
14	Oregon	Sept. 1988
15	West Virginia	Jan. 1989
16	Utah	April 1989
17	<i>Wyoming</i>	June 1989
18	Arkansas	July 1989
18	Virginia	July 1989
20	<i>North Carolina</i>	Feb. 1990
21	Ohio	June 1990
22	New Jersey	Jan. 1992
22	Tennessee	Jan. 1992
24	Nevada	Feb. 1992
25	Michigan	April 1992
26	Connecticut*	July 1992
27	Louisiana	Feb. 1993
28	Texas	Feb. 1994
29	Nebraska	Sept. 1995
30	Florida	July 1997
31	New Mexico	Jan. 1998
32	<i>Iowa</i>	July 1998
33	Alaska	Spring 1999

States in *italics* offer only confidential testing and not anonymous testing. All other states offer anonymous testing. ^ Oregon only requires named HIV reporting for infections in children <6 years of age and in limited other circumstances.

*Connecticut only requires named HIV reporting for infections in children <13 years of age.

The *Virgin Islands* also require name-based HIV reporting. This table is based on CDC data as of February 1999.

Interestingly, when states instituted named reporting of AIDS cases in the early 1980's, little public or political controversy surfaced.^{2,3} The Virginia Joint Legislative AIDS Subcommittee, formed in early 1989 to study HIV reporting, took the confidentiality issue into consideration when it endorsed the initiation of 16 additional anonymous testing sites (ATS) statewide. Four ATS had previously been established in 1985 to discourage blood donations from being the source of learning HIV serostatus (the additional sites in 1989 raised the total to 20). Given the *Code of Virginia* exemption status for ATS reporting, these additional testing sites continue to allow for more reasonable accessibility to anonymous testing for anyone concerned about confidentiality.

Opponents of HIV name-based reporting claim another pitfall to the use of names is that persons concerned about confidentiality go underground or avoid getting tested when reporting is mandated. In Virginia, a similar initial community viewpoint centered on the concern of potentially significant increases in ATS attendance, thereby reducing the benefits of named reporting. Retrospective analyses of Virginia's HIV testing data indicated attendance at ATS did increase from 1989-1992, as would be expected given the increase from 4 to 20 sites. However, the percentage of attendees at ATS clinics for any given year never rose above 14% of Virginia's total tests. (Table 1). In fact, HIV testing at ATS has steadily declined every year since 1992 (10,393 tests) to a low of 8% of all HIV testing in 1998. Confidential (name-based) testing increased in both 1996 and 1998.⁴ Nationally, from 1995 to 1997, anonymous tests declined

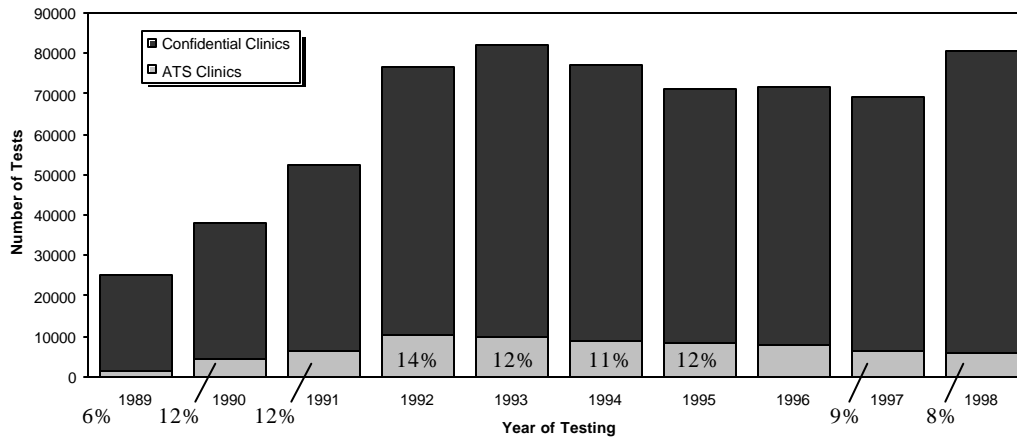
26.6% and confidential testing increased 3%.⁵ These results support the notion that HIV name-based surveillance can be implemented effectively and weakens the theory that such reporting has a negative public health impact.

Documentation supporting both name-based and unique identifier reporting exists. A recent study by *Woods et al.* concluded that HIV testing may decrease upon implementation of name-based reporting. However, the authors did not discuss the possibility of anonymous testing with study participants as an alternative for persons highly concerned about confidentiality. Regardless, 19% of participants, who were initially opposed to a named-reporting system, changed their minds after the benefits of HIV name-based reporting were explained.⁶

Benefits of HIV Reporting. The benefits of HIV reporting are useful for maintaining proper resources for prevention, education, treatment and support services. However, as alluded to previously, not all states require HIV surveillance. As of February 1999, ten states and the District of Columbia have no HIV reporting. Eleven states report HIV cases using unique identifiers instead of names.¹

Name-based HIV data supports enhanced HIV/AIDS surveillance activities, such as data matching to pinpoint record duplication or missing cases. It also allows for enhanced prevention and surveillance through partner notification and provides valuable information on HIV treatment. A CDC evaluation of unpublished name-based HIV surveillance data has indicated 74%-97% completeness of

Table 1. Virginia HIV Testing by Year



**Other/unknown" clinic types were excluded from analysis.

reporting and documentation of greater than 75% of risk exposures.⁷ A 3-year CDC evaluation of unique identifier reporting indicated that unique identifiers limit the performance of HIV surveillance and complicate risk-behavior data collection.⁷

HIV has increasingly become the staple epidemiological marker for HIV/AIDS surveillance. Historically, AIDS case reports were used as the standard measure of the HIV/AIDS epidemic. However, AIDS may not develop in a growing number of HIV-infected persons, due primarily to the effects of anti-retroviral medications. As these treatment regimens continue to slow the progression to AIDS, the result will be a decline in AIDS incidence, i.e. a reduction in new AIDS cases over a specified time period. Fewer persons progressing to AIDS means more HIV-infected individuals will remain within the HIV+ prevalent pool. Therefore it is imperative that HIV data be reported as accurately and as comprehensive as possible, so as to maintain sufficient epidemiological assessments.

The Division of HIV/STD began collecting AIDS case surveillance data in 1983. The

absence of HIV reporting during that time meant that vital prevention and partner notification activities were limited to AIDS cases. Six and one-half years later, upon the institution of HIV reporting, Virginia acquired the ability to collect information to fully assess and comprehend the extent of the epidemic.

Virginia's first ten years of HIV data reporting have demonstrated noticeable changes in trends and demographic variation, as observed in the accompanying statistical assessment. Results of this data have allowed the Division of HIV/STD to attain a clearer perspective of the distribution and determinants of HIV/AIDS in Virginia – an invaluable public health tool in the ever-changing continuum of HIV/AIDS prevention, education and treatment services.

Statistical Summary of HIV Reporting

Time Interval. In the decade between July 1989 and June 1999, the Division of HIV/STD received 11,357 HIV case reports. The number of reports steadily increased from 198 in July-December 1989 to peak of 1,647 in 1991. Reporting declined in 1992. The CDC issued a new AIDS case definition in 1993 that

increased the number of medical conditions that qualified as an AIDS case. Increased surveillance activity and increased physician awareness resulted in an increase in the number of HIV cases reported during 1993 to 1,496, the second highest level of the decade. The number of reported cases then fell to an average of 538 in the 3 six-month periods between January 1994 and June 1995. With the exception of 1997, which had an increase of fifteen cases over 1996 (from 980 to 995), the number of HIV cases reported has diminished annually. Based on January – June data for 1999, the number of cases for the year is projected to show an additional decline.

Age. The distribution of cases by age group has changed greatly between 1989 and 1999. In 1989, the majority (54.5%) of HIV cases was in the 20-29 year old group; the next highest group, 30-39 year-olds, represented 36.4% of reported cases. As the decade progressed, however, the proportion of cases among 20-29 year-olds declined consistently; in July-December 1990 it dropped below 40% and in 1997 fell below 30% for the first time. In January-June 1999, 24.4% of HIV infections occurred in this group. In contrast, the 30-39 year old group varied little from an average of 39.4% of reported cases with a high of 43.3% of cases in July-December 1995 and a low of 36.4% in July-December 1989. Currently, 30-39 year-olds account for 39.4% of all reported cases. HIV reports among people 40-49 years old increased throughout the decade. Beginning at 5.1% of cases in 1989, this group rose above 10% in the second half of 1990 (14.6%) and first crossed 20% in 1995 (20.2%). HIV reports among 40-49 year-olds have consistently been above 20% of all reports since the first half of 1997. Through June of 1999, the 40-49 year-old category consists of 23.2% of all cases. This figure is only slightly lower than the 24.4% of cases reported among 20-29 year-olds for the same period. Cases reports for people younger

than 20 and older than 49 increased during the decade. Those younger than 20 rose from 1.5% of reports in 1989 to 6.2% in 1999. People older than 49 began the decade at 2.5% of reports and ended it with 6.5%. The major change in the age distribution is that the proportion of HIV infections reported among patients 40 and older is increasing and the proportion among the 20-29 year old age group is decreasing.

Race. In 1989, the percentage of cases among blacks and whites was evenly distributed at 47.5% and 46.5%, respectively. Since then, these categories have diverged greatly as the disproportionate impact of HIV in African-Americans has become more dramatic. In the first half of 1990, African-Americans accounted for 64.6% of cases reported and white cases decreased to 31.7%. HIV reports for African-Americans varied between an early low proportion of 62.1% in the first half of 1991 and 69.8% in January-June 1995 before peaking at 73.9% in January-June 1996. Since 1997, an average of 70.4% of all HIV reports has come from the African-American population. The proportion of HIV reports from the state's Hispanic population has varied between a high of 5.1% in 1989 and a low of 1.8% in July-December 1990; the average for the ten year period is 2.7%. Collectively, American Indians, Alaskan Natives, Asian and Pacific Islanders and people whose race is other or unknown account for 1.2% of all reports for this period.

Sex. With the exception of the initial six-month reporting period, the female proportion of HIV reports has been consistently above 22% and has continued a gradual increase. The first indication of an active increase in female cases occurred in the second half of 1992 when the percent of cases increased to 27.3%. After remaining relatively stable (25% – 26.5%) from 1993 – 1995, the female proportion increased to 30.5% in July –

December 1996. Female reports averaged 29.8% between January 1997 and June 1999. The number of female HIV cases has declined from a high of 386 (26%) in 1993 to a low of 248 (30%) in 1998. This represents a comparative decrease of 138 cases; however, females now account for a larger percentage of all cases because the number of male cases has declined faster.

Transmission risk. Changes in the epidemic are evident from changes in the proportion of reports attributed to three primary adult transmission risks: men having sex with men (MSM), injecting drug use (IDU) and heterosexual. For male cases, MSM began the decade with 42.4% of cases but declined to roughly 35% in the first six months of 1990. The proportion of cases attributed to MSM has collectively declined in three noticeable stages between 1990 and June 1999. Between July 1990 and December 1992, MSM accounted for an average of 38.4% of cases. The average decreased to 35.1% between January, 1993 and December 1996 and then declined once again between January 1997 and June 1999 (31.8%). Although the number of cases declined during the ten-year period, MSM consistently remained the leading exposure category for HIV infection. Injecting drug use (IDU) varied as a percent of HIV reports. IDU increased from 20.4% of cases in the first half of 1990 to a peak of 25.7% in the same period of 1992. This transmission risk then began an overall decline. It decreased below 20% for the first time in January-June 1995. Between January 1998 and June 1999, the proportion of reported HIV infections attributed to IDU declined further and averaged 11.0%. In contrast to MSM and IDU, the proportion of reports attributing infection to heterosexual behavior increased between 1989 and 1999. Starting from 7.1% in 1989, the heterosexual proportion increased to 14.3% in the first half of 1990, and passed 15% in the last half of 1991, when it was 16.3% of all reports.

Heterosexual transmission peaked for the first time in July-December 1992 at 20%. It gradually increased to a second peak of 25.6% in the first half of 1998 before declining to 20.6% in the second half of 1998. As of June 1999, heterosexual transmission accounts for 22.1% of all HIV reports. Heterosexual transmission, an especially important factor in female HIV infections, passed IDU as the second most prevalent transmission risk in the first half of 1996.

Women. Because female HIV reports increased from 23.5% of the total in the first half of 1990 to 30.3% in the corresponding period of 1999 it is useful to consider trends in this sub-population. MSM is not a risk factor for female HIV infection so the pattern of transmission among females differs from male transmission. Heterosexual transmission is the dominant risk for women; it increased from 40.9% of reports in July-December 1989 to a peak of 54.4% in July-December 1992. After a decline in percent of cases in 1993, heterosexual transmission gradually increased to a peak of 56.2% of reports in January-June 1997. It has since remained stable at 46%-49%, which corresponds to the ten-year average of 47%. The second leading risk for females, IDU, tended to decrease during the decade. IDU reached a peak among female cases in the first half of 1993 when it increased to 37% of reports. Since 1993, IDU has decreased substantially. Despite a rebound in cases to 27.8% in the second half of 1995, IDU has steadily declined to less than 10% of cases in the first half of 1999 (8.7%).

The disproportionate impact of HIV on African-Americans as a whole is more pronounced in the female sub-population. In 1989, black female HIV reports were 63.6% of the total, with whites being 27.3%. The African-American female proportion increased gradually through the decade: it reached 80.6% in 1995; peaked at 85.2% in July-December 1997; and averaged 80.7% between

January 1998 and June 1999. Reports declined gradually from at least 20% through 1993 to a low of 11.6% in the second half of 1997. Despite an increase to 22.2% in the first half of 1998, the white female percentage has decreased to 13.6% through the first half of 1999.

Age trends for female HIV reports are similar to the trends in the set including males. The 20-29 year-old group declined from a high of 52.0% in the first half of 1990 to a low of 23.7% in the same period in 1998. The percent of reports from women in the 30-39 year-old group began and ended the ten-year period with only a 1% difference, despite year to year variation. Reports in the 40-49 year old group and among women older than 49 increased throughout the period.

Pediatric Cases. Pediatric cases include HIV infection of children between birth and thirteen years of age. Because the number of reports (124) between 1989 and 1999 is relatively low, minor changes from period to period have a large effect on percent distributions in categories. Perinatal transmission, which means HIV was transmitted from mother to child during pregnancy, delivery, or through breast milk, is the most common transmission risk. Of all reports, perinatal transmission accounted for 86.3% (107). Excluding one report from the first half of 1997 which is classified as a no identified risk (NIR) case, 100% of pediatric cases have been associated with perinatal transmission since January 1994. Between July 1989 and June 1994, fifteen reports indicated hemophilia or transfusion as the risk exposure.

Geographic distribution. Regional differences in HIV reports exist. The highest percentage of reports usually comes from the Eastern region which has varied from approximately 35% to 50% of reports in each six month interval; the ten-year average for this region is 39.2% of HIV reports. The

Central Region accounts for an average of 26.2% of all HIV reports for the ten-year period. Although Eastern typically accounts for more cases, Central has passed Eastern during three different six month intervals: July - December 1991, January - June 1993 and the first six months of 1999. Percentages of reports from the Northern region are similar to Central region reports but are usually lower; the Northern region has averaged 20.7% of all reports during the decade. However, HIV reports from this region increased gradually from a mid-decade low of 13.8% (July-December 1995) to 21.8% in the first half of 1999. The Southwest and Northwest regions contribute a smaller proportion of reports; the average for Southwest is 8.6% and the Northwest average is 5.2%. The differences in regional distribution of HIV infection reports that existed in 1989 still existed in 1999. The same conclusion can be made about the distribution of reports from rural and urban areas.¹ HIV infection in rural areas has increased slightly. Rural reports varied between a low of 5.6% in 1989 and a high of 14.7% in the first half of 1997 and averaged 10.1% for the decade. Generally, the geographic distribution of HIV reports during the ten-year interval has been less variable than changes in age distribution, race, sex and transmission risk.

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ⁱ Reports from locations within a Metropolitan Statistical Area (MSA) are classified as urban. All others are rural.